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Health and Government  
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*Subcommittees*

Government Operations  
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**March 9, 2022**

**Support Testimony for HB1020 - Developmental Disabilities Administration –  
Self-Directed Services (Self-Direction Act of 2022)**

The Honorable Shane Pendergrass, Chair  
Health and Government Operations Committee  
Maryland House of Delegates  
6 Bladen Street, Room 241  
Annapolis, MD 21401

Chair Pendergrass, Vice-Chair Pena-Melnyk, and Esteemed Members of the Health and Government Operations Committee:

HB 1020 is the culmination of years of work between advocacy organizations, self-direction participants, the Maryland Department of Health (MDH), and the Developmental Disabilities Administration (DDA). At the direction of the HGO chair, I facilitated a workgroup during the 2021 interim session to identify potential service gaps in the self-direction program, funding opportunities through the Centers for Medicare and Medicaid Services (CMS), and recommendations to strengthen service and support options for self-direction participants. The General Assembly members were Senator Lee and Delegates Belcastro, Bagnall, Bhandari, Kipke, Reznik, and Valentino-Smith.

In 2005, the Maryland General Assembly passed the new directions waiver. This new nationally acclaimed model allowed individuals with developmental disabilities to direct their healthcare, including their budget, employees, and treatment plan. In 2013, the program's name was updated to self-direction after merging with the community pathways waiver.

While the name change was welcome, many participants and their caregivers began reporting tighter restrictions on services, decreasing support options, and limiting control over their healthcare decisions. HB 1020 seeks to reverse this limiting trend and restore the original vision and intention of the 2005 landmark new directions waiver.

***Through the 2021 interim session workgroup, we identified eight recommendations that would positively impact self-direction participants. These include overnight supports, enhancing support broker responsibilities, better training of coordinator of community services, transportation flexibility, utilizing the budget of individual family goods and services, prohibiting the use of competency testing, greater budget transparency, and payroll parity.***

Critically important, these changes will have minimal, if any, financial impact on our state budget. Despite the fiscal note from the 2021 session, our workgroup identified the expansion of these services and supports are currently covered by the federal government's community pathways waiver. Additionally, the workgroup identified current services covered by the CMS waiver if the Department of Health would submit for those reimbursements. ***Currently, we are leaving federal financial support on the table.***

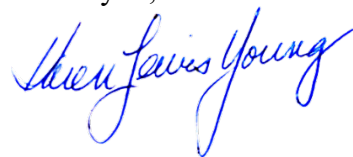
Simply put, this bill increases opportunity and flexibility for our communities' most vulnerable populations. We heard dozens of stories from participants, support brokers, coordinators of community supports, and caregivers expressing the need to have self-direction operate the way it was initially intended, as a customizable program that recognizes one size does not fit all. Testimony reinforced the many unique needs of each user and how they differed from person to person. Under the current system, everyone is forced into the same funding program that may or may not meet their immediate or long-term needs.

Self-direction saves the state of Maryland every year from increasing case demand through standard provider services and lowers the rate of institutionalization, a process that can cost taxpayers tens of millions of dollars over their lifetime. Frequently, institutionalization is neither in the participant's best interest nor the family's. We should actively support this cost-saving, person-centered decision-making approach for people with developmental disabilities.

When Maryland passed the original self-direction bill in 2005, our state was heralded as a leader in the effort to destigmatize disabilities and provide autonomy and agency for every person. Since that time, many states have replicated and expanded on our original program. I hope this committee will take the first step to reaffirm our position as a leader on the national stage to provide support and dignity to our disability community.

I ask for a favorable report.

Thank you,



Delegate Karen Lewis Young



**Final Report of the Workgroup to  
Review and Recommend Policies for the  
Maryland Self-Direction Program**

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Annapolis, Maryland  
March, 2022

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**Final Report of the Workgroup to Review  
and Recommend Policies for the Maryland  
Self-Direction Program**

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**Maryland General Assembly  
Office of Delegate Karen Lewis Young  
Annapolis, Maryland**

**March 7, 2022**

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March 7, 2022

The Honorable Shane Pendergrass, Chair  
Health and Government Operations Committee  
Room 241  
House Office Building  
Annapolis, MD 21401

Chair Pendergrass:

Enclose is the report of the Workgroup to Review and Recommend Policies for the Maryland Self-Direction Program.

The workgroup spent the interim thoroughly evaluating the complex system of programs and waivers contained within the self-direction program. During our seven public committee meetings and six public subcommittee meetings, we heard testimony from dozens of expert witnesses, advocacy organizations, participants in self-direction, caregivers, and representatives from The Maryland Department of Health (MDH) and Developmental Disabilities Administration (DDA).

In addition to our workgroup, I organized two subcommittees. One subcommittee reviewed the application of Center for Medicare and Medicaid Services (CMS) waiver services to ensure that Maryland was accessing all the funds available for self-direction participants. The second subcommittee provided participant analysis and suggestions to strengthen the self-direction program. Each workgroup meeting studied written materials, presented best national practices, and provided equal opportunity to present and debate various aspects of the self-direction program.

As a result, the workgroup has put forward nine recommendations set forth on pages 3 through 5 of this report. I am proud of this work product and believe that these recommendations are sound, necessary, and consistent with the original intent of self-direction. In response, I have filed HB 1020 – The Self-Direction Act of 2022, which incorporates each of these recommendations.

It has been a privilege and pleasure to serve as chair of the workgroup, and I thank you for giving me this opportunity to guide the work of this important body. I look forward to a productive legislative session incorporating much of this work to strengthen our self-direction program.

Sincerely,

A handwritten signature in blue ink that reads "Karen Lewis Young".

Karen Lewis Young



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**Workgroup to Review and Recommend  
Policies for the Maryland Self-Direction Program  
2021 Interim  
Membership Roster**

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**Delegate Karen Lewis Young, Chair**

**Senate Members**

Susan Lee

**Delegate Members**

Heather Bagnall

Lisa Belcastro

Harry Bhandari

Nicholaus Kipke

Kirill Reznik

Geraldine Valentino-Smith

**Public Members**

Ken Capone

Laura Howell

Ande Kolp

Rachel London

Serena Lowe

Megan Rusciano

Patti Saylor

Esther Ward

Alicia Wopat

**Maryland Department of Health Members**

The Honorable Bernard Simons

Heather Shek

**Workgroup Staff**

Erin Hopwood

Kristopher Fair

Melissa Bender





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# Workgroup to Review and Recommend Policies for the Maryland Self-Direction Program

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## Introduction

In 2005, the Maryland General Assembly passed House Bill 988, which included the creation of self-direction for participants with developmental disabilities (titled in 2005 as New Directions). The bill's passage was considered a national model for providing a participant-centered approach to healthcare that ensured the individual's treatment plan values and interests were respected and they are able to avoid institutionalization.

Over the last few years, advocacy organizations and participants have reported changes to the services available to people practicing self-direction. After submitting a formal request, House Health and Government Operations member Karen Lewis Young was notified on April 1, 2021, of authorization to form an interim workgroup. The Workgroup would comprehensively review the existing policies for the self-direction program and make recommendations to restore and strengthen the program for its participants. Delegate Lewis Young was appointed to chair the Workgroup.

The Workgroup was charged with:

- Reviewing and understanding the self-direction model for participant-led healthcare.
- Determining if program accessibility and flexibility have decreased.
- Identifying and collating the needs and gaps for individuals practicing self-direction.
- Investigating financial concerns by reviewing existing CMS waivers for participants

## Meetings

The Workgroup met from June through December during the 2021 interim. Thirteen public meetings were held where experts and participants presented data on various policies, procedures, and regulations impacting the self-direction program. The Maryland Department of Health discussed existing processes and answered committee members' questions. In addition, dozens of citizens provided testimony. Every meeting included the opportunity for public comment. Every workgroup member actively participated in a thoughtful and robust discourse throughout each session, resulting in comprehensive recommendations.

Recordings of the following meetings were published through youtube:

- August 25, 2021: <https://youtu.be/3Q2biAsSic0>
- September 28, 2021: <https://youtu.be/zfPhnCoyXgo>
- October 27, 2021: <https://youtu.be/dqS3l3Au6rk>
- December 29, 2021: [https://youtu.be/Q\\_jGt\\_priT4](https://youtu.be/Q_jGt_priT4)

## **June 30, 2021 Meeting**

At its first meeting, Health and Government Operations Vice-Chair Joseline Pena-Melnyk and Workgroup Chair Karen Lewis Young welcomed everyone. The committee's composition was outlined, and the initial review of our Workgroup's mission. A video developed by the Self-Direction Advocacy Network of Maryland, Inc. (SDAN) was shared to understand the benefits of the self-direction program.

As the final agenda item, the Maryland Department of Health was finalizing a Request for Proposal (RFP) application for Fiscal Management Services (FMS) for self-direction. The committee and MDH discussed the various components of the RFP for potential updates.

## **July 28, 2021 Meeting**

The Workgroup hosted an expert from the Administration for Community Living (ACL) to discuss the federal framework for self-direction. Specifically, they discussed available federal waiver options available to participants of self-direction. Next, a long-term support broker in Maryland presented a history of self-direction from its introduction in 2005 to today. MDH also briefly updated the committee on the status of the FMS RFP.

## **August 25, 2021 Meeting**

Chair Lewis Young announced the formation of two new subcommittees. One subcommittee will review the existing CMS waivers and identify potential waivers that Maryland does not currently utilize. The second subcommittee will be a participant-led committee to help identify and provide solutions to gaps in the self-direction program.

Next, a panel of self-direction experts presented challenges and options with various components of self-direction. These components included challenges with competency testing, designated representative requirements, allowances for house managers and administrators, access to overnight supports, the process by which participants may hire family members to provide supports, and allowances for the administration of medications.

## **September 28, 2021 Meeting**

The Participant's subcommittee reported to the general Workgroup on the meeting minutes of their first meeting. The committee outlined challenges they identified, including shortages of direct support professionals and support brokers, the desire to remove or minimize the role of designated representatives, a need to re-evaluate the transportation fee schedule, and the need to recruit and retain new people to the field.

Additionally, the CMS subcommittee reported their first meeting, including the CMS response letter to an inquiry filed by Representative David Trone. The committee reviewed the CMS waivers for overnight supports, support brokers, and habilitative supports.

## **October 27, 2021 Meeting**

The fifth meeting focused on the experiences of various people working within the self-direction program. The panel consisted of a support broker, a former Maryland Coordinator of Community Services (CCS), a family member caretaking for a person in self-direction, and a self-direction participant. MDH provided data on the growth of self-direction. CMS subcommittee provided an overview policy matrix of various policies, federal guidance, and recommended reforms.

## **November 24, 2021 Meeting**

At the November meeting, the committee began framing out a list of recommendations for the Workgroup to consider. Utilizing the feedback from the CMS and Participants subcommittees, the Workgroup built a list of requested changes to current policy and discussed what policies needed to be addressed on an administrative level versus a legislative level.

## **December 29, 2021 Meeting**

SDAN provided guidance on a few additions to the Workgroup's recommendations at the final meeting. The Workgroup reviewed and discussed the definitive list of recommendations and built a final matrix outlining the suggested changes to various programs available to self-direction participants. Chair Lewis Young also reported meeting with MDH representatives regarding the committee recommendations. She said that MDH has agreed to one recommendation and would change that policy internally. Finally, Chair Lewis Young informed the committee that she had forwarded the recommendations to Legislative Services (MLIS) to draft them into a bill for the 2022 session.

## **Recommendations**

The Workgroup issued nine recommendations to provide greater access and flexibility to self-direction participants. These recommendations have been incorporated into House Bill 1020 and are set forth below.

### **Recommendation 1 – Overnight Supports and Personal Supports**

- Reinstatement full employer authority for all personal supports to self-directed participants.
  - Include those with an established need for overnight supports.
  - Include those living independently or in their family homes.
- Amend the current Community Pathways Waiver to allow the State to receive Medicaid federal matching funds.
- Remove the 82-hour limit on personal supports under the current CPW waiver.
  - Personal supports would be determined *based on individual needs*.

## **Recommendation 2 – Support Brokers**

- Increase Support Broker hours from ‘up to four hours per month’ to ‘up to forty hours per month.’
- Restore support brokers’ responsibilities to match the federal CMS position description.
- Enact a policy that requires a third-party support broker to be hired if the individual hires a family member or guardian as paid staff.

## **Recommendation 3 – Coordinator of Community Services**

- Invest in increased training for the Coordinator of Community Services.
  - Training includes proper policies, resources, and roles.
  - How to work with transitioning youth, individuals without strong family supports, and historically disadvantaged communities.
  - Budget allocations whenever self-direction is changed through legislation to ensure proper education training about the changes.

## **Recommendation 4 – Transportation**

- Expand coverage of transportation services to allow for mileage coverage to owners of vehicles who are not paid staff but are supporting participants under self-direction.
- Expand coverage of transportation services to allow for mileage reimbursement to non-employee owners of vehicles used by the participant for plan goals and activities.
  - Update the necessary DDA waivers to reflect this change.

## **Recommendation 5 – Individual and Family Directed Goods and Services**

- Create more flexibility with Individual and Family Directed Goods and Services
- Remove the five-thousand-dollar cap on IFDGS
  - IFDGS would be determined *based on individual needs*.
- Allow participants to self-identify their IFDGS without constraints
  - Ensure the participant stays within their budget
  - Ensure their budget matches the provider-based model

## **Recommendation 6 – Competency Testing**

- Eliminate competency assessment in any form from all DDA policies and proposals.

## **Recommendation 7 – Budget Transparency**

- Allow participants to access the Long-Term Services and Supports Computer System (LTSS)
  - Ensure plans and budgets are easily accessible.
  - Ensure the funding is consistently updated for tracking.

## **Recommendation 8 – Provider Managed and Self-Direction Parity**

- Codify in regulation the parity in budgets and compensation for individuals participating in the self-direction program, so they align with the budgets and compensation for individuals utilizing a provider-managed program.

## **Recommendation 9 – Annual Report**

- The Developmental Disability Administration (DDA) will provide an annual update to the Maryland General Assembly for three years outlining its implementation and relevant outcomes of the Workgroup’s recommendations.

## **Conclusion**

The Workgroup extends its appreciation and gratitude to the Maryland citizens who participated at each Workgroup meeting. Your input and involvement are invaluable to identifying the self-direction program's strengths and the opportunities to increase participants’ positive outcomes. The Workgroup would also like to thank the Health and Government Operations staff, Maryland Department of Health, and the following individuals who assisted by providing testimony or serving on the Participant’s subcommittee:

- JP Shade
- Carmen Hudlud
- Mat Rice
- Thomas
- Rob Stone
- Jeneva Stone
- Sunny Cefarratti
- Carol Custer
- Susan Goodman
- Barbara Reff
- Alarice Vidale de Palacios
- Irene Souada
- Karina Jones
- Karen Blanchard
- Patricia Eisenberg
- Marla Hollander
- Beth Monroe
- Gail Goodwin
- Kate
- Paulette
- Lisa Lorraine

The Workgroup members look forward to working on the legislation incorporating its recommendations and seeing that legislation through to passage and enactment.